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THE SOCIAL CONSTRUCTION OF UNIQUE CARING RELATIONSHIPS: METAPHORS AND DESCRIPTORS OF AIDS AND MUTUALITY IN BUDDY DYADS

By

Renee Maday

RECOMMENDED:

Advisory Committee Chair

Department Head

APPROVED:

Dean of the College of Liberal Arts

Dean of the Graduate School

4-3-97

Date

THE SOCIAL CONSTRUCTION OF UNIQUE CARING RELATIONSHIPS: METAPHORS AND DESCRIPTORS OF AIDS AND MUTUALITY IN BUDDY DYADS

A

THESIS

Presented to the Faculty

of the University of Alaska Fairbanks

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for the Degree of

MASTER OF ARTS

By

Renee Maday, B.A.

Fairbanks, Alaska

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Abstract

This study explores how acquired immune deficiency syndrome (AIDS) is socially constructed in buddy dyads as revealed by the written metaphors and descriptors supplied by cultural members through a survey instrument. A buddy dyad consists of a volunteer caregiver and a person with AIDS (PWA). The metaphors and descriptors that the buddies recounted provide an understanding of these special relationships and the social construction of AIDS in this uniquely affected population.

Analysis revealed that AIDS is most often constructed as integral to community and activism in the AIDS Culture. The buddy relationship is most often constructed as a friendship rather than a caregiver/client relationship. The participants also revealed that buddy dyads are both life-affirming and significant relationships. The examination of buddies' metaphors and descriptors further suggests that their lived experience with AIDS is uniquely different than the construction of AIDS most often made by the media and the rest of U.S. culture.

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Acknowledgments

Nigh on two years ago, with a dizzying mix of trepidation and delight, I left my home to travel over 4,000 miles to pursue my goals of earning a Master's Degree in Communication and living in Alaska. When that journey North was complete, the real expedition began.

The true trek was an odyssey of understanding and re-construction of self as I maneuvered through the new experiences of being a graduate student, a teaching assistant, and becoming a scholar. I express much gratitude to my Chief Navigator on this challenging excursion, Dr. Pamela McWherter, my Thesis Advisor, Professor, and treasured Mentor. I thank her for her masterful navigation which came in the form of sound advice, frequent encouragement, and thoughtful tutelage. I likewise express gratitude for her generous spirit and wicked wit which made the journey enjoyable.

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Many thanks to Dr. Jin Brown for serving on my

Thesis Committee and for challenging me at every turn. From interaction with him, I have learned fortitude and much more about not only the discipline of Communication but life itself. I also praise him for his generosity in sharing both his valuable personal reference materials and the priceless gift of his time.

I now wish to recognize the yet undiscussed member of my Thesis Committee, Dr. John Leipzig. I thank him for his toil on my behalf and additionally commend him for his invaluable stewardship of the Communication Department at the University of Alaska Fairbanks during his tenure as Department Head. He carries through this tireless role with unmatched finesse which is truly appreciated. I hope that his infectious enthusiasm travels with me as I move on to other venues.

I would be remiss if I did not express sincere thanks to each of the individuals who took the time to return the survey instrument used for this research. In the stresses of life in this era of AIDS, it would have been easy to overlook my request for participation in this study. I applaud your efforts to add to our understanding of the complexities of life with AIDS.

Finally, I thank all the travelers who ventured heretofore.

Chapter 1

Introduction and Research Questions

Introduction

This study examines metaphors and descriptors created by members of buddy dyads in order to understand how acquired immune deficiency syndrome (AIDS) is socially constructed by persons involved in these unique caring relationships. A buddy dyad consists of a volunteer care-giver and a person with AIDS (PWA). Many cities in the United States have community-based organizations to assist PWAs. These organizations are often multi-focused with programs that may include education campaigns, food banks, fund raising, hot lines, legal advocacy, political lobbying, medical care, and/or non-medical assistance to PWAs. Programs involving the buddy dyad are common to many AIDS-related organizations that hope to provide their clients/PWAs with supplemental, non-medical care. The term "buddy" is used to refer to both members of the dyad, PWA and volunteer; for the purposes of this study the two will distinguished by pairing labels. The buddy/volunteer offers her or his buddy/PWA basic assistance in living with AIDS. The buddy/volunteer may perform many tasks such as running errands, light

housekeeping, and providing transportation. The buddy/volunteer may also organize recreational activities with consideration to possible physical limitations of the buddy/PWA. Perhaps the most valuable, yet difficult task, is providing emotional support to the buddy/PWA as she/he confronts the myriad of issues arising as the disease ravages her/his body and perhaps previous support networks as well. The importance of the buddy/volunteer's role in providing emotional comfort to the buddy/PWA is crucial because many would-be supporters sometimes distance themselves from the PWA out of fear of infection, helplessness, resentfulness, or emotional "burnout" (Kaplan & Toshima, 1990). A buddy/volunteer may provide excellent emotional support for her/his buddy/PWA because she/he has neither a history with the individual nor the overwhelming everyday responsibility for the individual's care (Silver, Wortman, & Crofton, 1990).

Buddy dyads, which are assumed to be supportive, have been selected as research subjects in order to understand these special relationships. Through metaphors regarding AIDS that members produce, this study seeks to understand buddy dyads as well as possibly extending our understanding of the social

devastation of the AIDS epidemic. Metaphors created in such settings provide a deeper understanding of the social construction of the AIDS epidemic in this uniquely affected population, as well as the social construction of the buddy relationships themselves.

Research Questions

This research sought understanding of the multiple issues of AIDS as lived experience, and so posed the following research questions:

1) How do members of buddy dyads construct AIDS as revealed in their written metaphors?

2) Do members of buddy dyads construct AIDS more positively, as, for example, a challenge (or series of challenges) to be met and overcome, more so than negatively, as in the metaphor "AIDS is death," or judgmentally, as in the "AIDS is the wrath of God" metaphor?

3) How do buddies construct metaphors about their buddies, and what understanding can be gained about the experience of the buddy dyad relationship through an examination of these metaphors?

Chapter 2 examines the issues foundational to this study. These include: metaphors, the social construction of reality, AIDS, PWAs, and buddies.

Chapter 2

Metaphors, Social Construction, AIDS, PWAs, and Buddies

A Metaphor is a Vehicle that Transports Meaning and a Machine which Constructs Meaning

Metaphors are a part of every aspect of our life, central to the perceptions of humans and the social construction of lived experience (Lakoff & Turner, 1989). They are central to our understanding of ourselves, and of our cultures. Metaphors are the merging site of mind and culture. Humans use metaphors, from early childhood on, to make life comprehensible by using comparisons when literal explication might fail or be too cumbersome, i.e., to enliven and clarify spoken messages (Goldberg, 1990). Metaphors function both interpersonally and intrapersonally as tools for understanding. As such, metaphors are not just the words we speak; they also frame our thought processes and motivate much of the actions upon which we embark. Human conceptual systems are fundamentally metaphorical in nature (Lakoff and Johnson, 1980). How humans formulate perceptions, learn, understand, and relate to others are metaphorical processes. Metaphors are "vital" in the construction of reality and the construction of self (Wolf, 1994).

Metaphors enhance both the understanding of, and the experiencing of, one concept by creating a comparison to another. Such comparisons occur both consciously and habitually; they are a constant in language, thought, and action. Metaphors come to the rescue when normal language is "inadequate to bridge the gap between the abstract and the concrete" (Pearce, 1996, p. 2). Humans need metaphors to give structure to abstract concepts such as emotion, time, and cognition through pairing with more easily grasped concepts such as spatial orientation, and objects. Metaphoric interconnection is a matter of what gets defined/understood and what does the defining/structuring (Lakoff and Johnson, 1980).

Metaphors are cultural constructs that keep members of a given culture in agreement concerning the relative value or importance of one item coupled with the norms surrounding the item or action being metaphorically discussed, acted on, or reflected upon. These expressions form, hold, and allow the transfer of meanings of a culture. Cultural members understand one concept in terms of another because particular metaphors are prominent in the culture. This process allows one to gain understanding "beyond the range of

ordinary literal ways of thinking and talking" (Lakoff & Johnson, 1980). Metaphorical sets are the distinctive "shorthand" (Pearce, 1996, p. 10) that members of a specific culture use to establish, understand, reveal, and maintain membership in the culture.

Fundamentally, metaphors are a literary technique found in all types of narratives; however, in lived experience they act as cognitive mechanisms which structure our thoughts and actions so that meanings are constructed. As such, they provide an economical means of compressing communication by conveying vast amounts of information organized within cultural norms and historical perspectives. Thus, metaphors provide a convenient means of accessing stored information (Pearce, 1996) and a simpler way to order language and constuct meaning.

Metaphors are richer, more complete, than simple descriptions. Main points may be more easily understood and remembered when worked into vivid metaphorical constructions. Metaphors are "data-producing and pattern-making devices," (Kvale, 1996, p. 275) and serve humans as vehicles that allow movement from the cognitive to the affective world of feelings or the reverse. This function opens up the literal world to

the conscious, cognitive world to the affective world, and back again as human beings interact. Such mobility allows for the whole range of humanness.

One cannot think without metaphors acting to interpret and compress thought. Metaphorical imagery is a rhetorical and semantic device through which meaning can be interpreted. A metaphor illustrates the likeness (or unlikeness) of two concepts. Their use by social actors in both interaction and cognition is revealing of each person's construction of self, culture, and lived experience, i.e., metaphors reveal a group's taken-for-granted "shared" meanings and common knowledge (Coffey & Atkinson, 1996).

It is important to note that standard vocabulary (with rules of applications and limited interchangeability) and the literal meanings of the vocabulary, however expansive and varied, are in no way adequate to handle the myriad of meanings each human requires to navigate through thought, action, and communication. The literal meaning of a word is important to the metaphorical expression or thought; it is not diminished, but rather heightened by its integration with a new or more figurative construct. This elevation is particularly significant in

predominantly emotive communication (Mooij, 1976). In addition to elevation, metaphor also allows for efficiency and economy in language and thought. New concepts are conveyed in a short (economic) and easy-to-grasp (efficient) manner. They provide humans with the needed apparatus to cognitively explore and interpret new situations, and yet find our way back to the familiar. Metaphors are powerful tools that enable one to understand, describe, interpret, and elucidate what is new in terms of what has been previously processed and understood. These tools play a central role in the assimilation of experience (Mooij, 1976).

Each metaphorical phrase has two subjects, a principal subject and a secondary subject. Both subjects are systems of belief, or constructions of reality; they lose their individual characteristics. When one interprets a metaphor, she or he constructs a set of beliefs about the principal subject parallel to the set constructed about the secondary subject. The two subjects interact in the co-joined interpretation with one subject highlighting some characteristics of of the other while other traits are suppressed. The belief systems undergo a metamorphosis so that the secondary subject is now constructed within a framework

supplied by the primary subject (Tourangeau, 1982).

Identifying Metaphors

Metaphors can be delimited from literal language in several ways. 1) The linguistic context and/or non-linguistic situation is such that the participant(s) is (are) clear that the utterance or thought is about a specific concept. 2) The words have a field of literal descriptive meaning determined by semantic conventions. 3) The words are used in a way that they characterize certain aspects of one concept in comparison to another. 4) It is evident that aspects of one concept do not literally describe the features of the other concept. 5) The utterance or thought is not nonsensical and is understood as a significant contribution to the discourse (Mooij, 1976).

Types of Metaphors

Three types of metaphors can be delineated by the function they perform. Some metaphors function as: representational acts; collective paradigms and images; and connecting links between events and meanings (Yerby, 1989).

Metaphors classified as representational acts are behaviors or messages that serve as symbols for other behaviors or messages. As such, they describe how

certain communication interaction actually represents others (Yerby, 1989).

Those characterized as collective paradigms and images are symbols, adjectives, or events that are descriptive to the specific cultural context (Yerby, 1989). The context is important because different cultures develop central metaphors for the collective experience of members past and present.

Finally, metaphors categorized as connecting links between events and meaning involve a process of translation that frames a specific experience or event in a way which produces meaning (Yerby, 1989). This process is culturally bound in that it allows each individual member of a culture to perceive herself/himself, membership in the culture, and the culture itself in meaningful ways through an understanding of the essential meaning(s) of a particular event.

The Process of Metaphorical Understanding

The process of understanding metaphors is a two-step process; metaphors are interpreted literally and then figuratively. The literal meaning is rejected because it does not fit the existing patterns of understanding. Rejection of the literal leads to the

figurative construction which is built as one gathers shared attributes that distinguish how the secondary subject is to be used to gain an understanding of the primary subject.

This two-step process begins in the recognition stirred by the juxtaposition of two very different subjects and the need for reconciliation of the differences. The nature of the two pre-existing belief systems are determined, then, a new construction for the primary subject is interpreted from an understanding of the secondary subject. The process concludes with a re-analysis of the two belief systems as newly, and mutually, constructed by the juxtapositioning process (Tourangeau, 1982).

Humans arrive into a world constructed in part by metaphors, but as individual and cultural experiences accumulate and change over time, new constructions develop from the same metaphors. These new metaphors are altered by a succession of metaphors that more clearly capture the individual or cultural situation. Through time, transitions between and among metaphors occur because constructed realities (in part constructed by the metaphors) change and the central meaning of the metaphors change concurrently (Owen, 1990).

Rationale for Pursuing Metaphorical Research into AIDS and Buddy Dyads

Metaphors are important language tools which help humans organize how to think about information and to create meaning in regard to experience. They permeate language and influence the construction of opinions (Lupton, 1991). Metaphors allow people to convey meaning verbally (Lakoff & Johnson, 1981) and help individuals crystallize how they conceptualize the world; therefore they cannot be avoided when speaking and thinking about AIDS and the buddy relationships.

Past research (Lupton, 1991; Clatts & Mutchler, 1989; Hughey, Norton, & Sullivan-Norton, 1989; Ross, 1989; Sontag, 1989) involving participants from the general population, college students, and physicians, plus analysis of various media accounts, reveal that AIDS metaphors often reflect constructions of judgmental attitudes relating to PWA's assumed sexual orientation, promiscuity, and blame-worthiness. Commonly repeated metaphors imply that AIDS is a kind of divine retribution or punishment of a person who deserves punitive justice. A metaphor illustrative of this construction is: "AIDS is the wrath of God." Still other metaphors associate AIDS solely with death, as in

the metaphor: "AIDS is death." This type of metaphorical construction reveals nothing about the impact of AIDS on the socio-cultural landscape of the United States. Also, death-themed metaphors do not reflect that a person with AIDS "lives" with the disease, often for many years, before she or he dies with the disease. An important distinction must be made here in that many PWAs prefer to have AIDS perceived as a life-threatening disease rather than as an inevitable death sentence (Norton, Schwartzbaum, & Wheat, 1990).

The more apparent function of metaphors is that they enable humans to assimilate, in light of the familiar, what is unknown or unnamed. However, metaphors also contribute insight into what may be too well known to allow for a new perspective; thus are conducive to both the development of entirely new viewpoints, and the reconstruction of old viewpoints (putting a concept in a "new light"). Two decades of the cultural experience of AIDS notwithstanding, the many meanings of AIDS and the AIDS Crisis are still unnecessarily convoluted. A significant portion of the population remains uninformed in regard to persons with AIDS and various AIDS-related issues. This study seeks to partially rectify this educational void.

Perhaps the research participants will also have the opportunity to construct new and productive insights into their own realities.

The Social Construction of Reality Theory

The social construction of reality theory begins with the assumption that communication is a never-ending, always changing process that creates our social world and its meanings. Furthermore, the theory holds that communication acts are understood within a specific time and place (Littlejohn, 1996).

Social construction also examines how meanings and understandings develop as we communicate with others. It supposes that all communication acts are voluntary and assumes that knowledge is a product of interaction within social groups. Social construction theory posits that meanings produced in social interactions are contextual, and subject to change as time and place change. The social construction theorist also recognizes that her/his act of research is value-laden and in itself creates social worlds (Littlejohn, 1996).

Furthermore, this theory deals with how social worlds are created through human interaction. A social world is created through communication; i.e., words, symbols, and behaviors (Leeds-Hurwitz, 1995). Meaning,

defined by symbols, allows humans to construct a socially shared world. The scope of that social world determines the available channels of communication.

The role of language in social constructionism is an important area of focus when examining the person with AIDS and all those whose lives are impacted by AIDS. Reality is created through interaction by the use of symbols, especially language. Through language, persons attempt to understand the meaning others hold for an object or event. Conversation links humans to one another by orienting us to shared goals, values, institutions, and ways of life, thus greatly influencing perceptions relating to self. Language is a means of organizing and structuring the world because it is a means of symbolizing and representing all experience. Language also facilitates constructions which belittle certain groups within society by invalidating particular symbols.

The social construction of reality views human communication as a social accomplishment. This theory attempts to determine how humans communicate, how we create our social identities and roles, and how we respond to the identities and roles of others within the society we co-create. Individuals construct

meanings from their incomplete experience within a social world. By focusing on the connection between the structures of a society and the behavior of members of a given group, social construction offers researchers a way to look at this dynamic culturally, and this study of the AIDS Culture specifically. It is important to emphasize that individuals are active agents in creating their own realities (Leeds-Hurwitz, 1995) and that any attempt to understand human behavior must begin by tracking persons in their everyday coping (Stewart, 1995).

Critical attention to language is fundamental to the social understanding of AIDS and individual responses to various AIDS-related issues. "AIDS is not simply a physical malady;" depending on the person or culture constructing it, AIDS may also be "an artifact of social and sexual transgression, violated taboo, fractured identity" or a variety of "political and personal projections" (Grover, 1988, p. 18). An examination of AIDS within a culture cannot produce a "neutral review of meaning" (Grover, 1988, p. 18).

Finally, metaphors are "intimately tied to thought and thus play a vital part in the construction of reality (and are) elemental to human understanding"

(Wolf, 1994, p. 28). Thus, this study examines the metaphors of members of buddy dyads in order to discuss the social construction of AIDS and the buddy dyad relationship.

AIDS is with Us

Acquired immune deficiency syndrome has been a part of U.S. social consciousness for over ten years, yet major gaps in our understanding still exist. With diverse social, cultural, political, and economic ramifications, the existence of AIDS calls on all members of society to increase their awareness of the problem, the course of the disease, and what one can do to help self and others.

The statistics are staggering. According to the United States Department of Health and Human Services (AIDS Hotline, February 27, 1997) there have been 548,102 reported AIDS cases in the United States with an estimated 8.4 million cases worldwide. They also estimate that between 650,000 to 900,000 United States citizens are HIV positive with over 30 million such afflicted worldwide.

In recent years, scientists have begun to unravel the mystery of AIDS. As knowledge about AIDS increases, so does our ability to live safely in society while

rising humanely to meet the many cultural challenges that this disease presents.

AIDS

AIDS is a malady in which the body's immune system deteriorates. As the immune system fails, a person with AIDS typically develops a variety of life-threatening illnesses and afflictions (Department of Health and Human Services, 1992). AIDS leaves the body unable to overcome certain infections that a healthy immune system can stave off easily. These "opportunistic infections" often develop from organisms (bacteria, viruses, protozoa, parasites, and fungus) that are commonly present in most humans and/or everyday living/working environments (Maxey & Gee, 1996).

AIDS is believed to be caused by the human immunodeficiency virus (HIV). A virus is a foreign invader to the body that attacks specific cells. A healthy body typically fights off viruses with a number of mechanisms, eventually defeats the invader, and the body is then restored to health. HIV, like some other virulent viruses, has the capacity to mask itself and become part of a host cell in the body. The body is then left defenseless because it no longer recognizes HIV as an invader (Sach, 1995). This is one of the many

reasons that finding a cure for AIDS is so complex.

Approximately 50% of individuals with HIV develop AIDS within 10 years, but the actual time between HIV infection and the onset of fullblown AIDS can vary greatly. Today's advances in medical treatments for persons with HIV can postpone their progression toward AIDS and also offer hope for those already diagnosed with AIDS (Department of Health and Human Services, 1992). Medical treatment depends on the opportunistic infection(s) already present. Treatment may include antibiotics, chemotherapy, radiation therapy, and/or drug therapy such as Azidothymidine (AZT). The importance of proper nutrition, good hygiene, rest, exercise, stress management, and a generally healthful lifestyle are also considered key to health maintenance for persons with HIV or AIDS (Maxey & Gee, 1996).

One can become HIV infected through anal, vaginal, or oral sexual activity with an infected person, or by sharing syringes with an infected person. Also, women infected with HIV can pass the virus to their babies during pregnancy, birth, or breast-feeding. A final risk for transmission is through blood transfusion; however, since 1985 this risk has been virtually eliminated in the United States because of exhaustive

protocols set in place to screen and laboratory test donated blood (Department of Health and Human Services, 1992). No existing evidence suggests that HIV or AIDS can be transmitted through casual contact of any kind (U.S. Department of Health and Human Services, 1996). HIV is not an airborne virus, and routes of transmission are very limited (Sachs, 1995).

Persons with AIDS

The diagnosis of AIDS alters previous constructions of meaning in one's life. Meanings develop as a PWA attempts to understand adversity and suffering that are part of living with AIDS. Meaning may be conceptualized to answer the pivotal question: "Why me?" Deriving meaning is influenced by both personal and cultural factors, and often provides a sense of beneficial, self-affirming attitude toward life and self (Kalichman, 1995).

One sense of meaning among PWAs is often produced by the conscious effort to live each day to the fullest. This may be evidenced by periods of great personal growth, self-awareness, inner strength, and resiliency. The PWA surprises herself/himself with how well each new obstacle is handled and this greatly impacts prior constructions of self. It is a learning

experience about significant others, society, and self. Such personal growth may further manifest itself by a greater appreciation for significant relationships in the PWA's life, a re-examination of values, and a renewed purpose in daily existence. Self-discovery may also produce greater appreciation for the aesthetics of life (Kalichman, 1995). A PWA often takes time to reflect on the beauty of nature, humanity, and self in a way never previously imagined.

The meaning of control is another pivotal aspect of living with AIDS. Constructions of control are borne from a sense of at least some mastery over AIDS. A sense of control buffers the effects of each new downward turn in health or other living situations brought on by the illness, and can be created with the maintenance of a positive attitude by self and significant others, combined with various coping strategies. Knowledge of and access to the latest developments in medical care, input into personal treatment options, and social support all bolster the PWA's sense of control (Kalichman, 1995).

The feeling of at least partial control is seen as necessary for psychological well-being among PWAs. Control can originate in one of two ways: internally or

externally. Internal control emerges from beliefs that various actions can change the progression of AIDS in self, e.g., thoughts of hope, a positive mental attitude, and the adoption of a healthy lifestyle. External control involves the belief that powerful outside agents impact the situation (Kalichman, 1995). The conception of outside agents reinforces the AIDS Culture's belief that the PWA and her/his caregivers must take an activist stance in fighting AIDS, and the powers that exist must be rallied behind this cause. Such powers include the government, the medical profession, and all key elements of society in this era of AIDS. Persons with AIDS must be empowered to chart their own personal health care and daily schedule as well as to create and implement public policy.

Buddy/Volunteers

The advent of AIDS in the 1980's stirred a volunteer response unparalleled in recent years (Arno, 1986). After an initial period of denial and slow response, AIDS-awareness increased and practically overnight AIDS service organizations were formed and volunteers were sought to meet the needs of persons with AIDS seeking help. Still other pre-existing gay-related organizations struggled to meet the additional

needs created by the AIDS epidemic. Many of these organizations grew rapidly in order to address the serious issues brought on by the new, mysterious illness that was beginning to be seen in gay men. The organization that served as this study's research setting falls into the latter category and grew from an initially small, inner-city gay men's organization to a large, multifaceted AIDS service organization serving Virginia, Maryland, and the District of Columbia.

With such expansions, a desperate call went out for volunteers. The call was answered as diverse people volunteered in the fight against AIDS. Volunteers came together to do what "many others in society were either unwilling or unable to do" (Kobasa, 1990, p. 280). Volunteer activities are many and varied including fund-raising, lobbying support, medical services, legal aid, food distribution, and administrative work. AIDS service organizations that provide PWAs one-on-one support interventions rely almost solely on these volunteers (Kalichman, 1995).

Some of these "foot soldiers" on the frontline of the AIDS Battle are titled "buddies." With the emergence of the AIDS epidemic, the concept of the "buddy" has taken on new meaning within the culture of

AIDS. Different AIDS service organizations have slightly different ways of structuring their buddy programs, but generally the buddy process involves volunteers from the community agreeing to be matched with a person with AIDS at some future time. Before the assignment is made the volunteers participate in formal training (O'Brien, 1992). Formal training includes educational sessions on HIV, the background of the illness, advances in medical care for persons with AIDS, and working with "sticky situations like parents, or lawyers, or the workplace" (O'Brien, 1992, p. 104). Additional training may involve discussions on insurance, medicare/medicaid benefits, substance abuse, coping strategies, stress reduction, communication skills, suicide, and the protection of self from HIV infection when working with a PWA. Training may also include discussion of attitudes about spiritual issues, homosexuality, ethnic diversity, and personal responsibility.

Ongoing training and emotional support is usually supplied during Buddy Team Meetings (Dumont, 1988), which typically occur monthly. Such meetings sometimes include speakers who provide new information and perspective; however, their essence is the opportunity

for the buddy/volunteers to share their experiences and their own emotional stresses as well as the surprising joys garnered during this time of service.

The buddy/volunteer gives her/his assigned buddy/PWA companionship and basic assistance as that individual faces the many challenges presented by AIDS. Such tailoring of her/his volunteer activities to the varied and ever-changing needs of the PWA to whom she/he is assigned is necessary; thus it is essential that members of the dyad talk openly and honestly about expectations and plans. Negotiated tasks performed by the buddy/volunteer may include organizing social outings carefully planned with consideration to the PWA's lesser stamina or mobility, mundane errand running or light housekeeping, or heart-wrenching talks about a death too soon. Buddy/volunteer visits also serve to give primary caregivers a much-needed respite as well.

Buddy/volunteers face vicissitude and stress as they offer assistance to a PWA struggling against the disease. The most significant burden associated with being a buddy/volunteer concerns the time commitment and emotional investment entailed (Velentgas, Bynum, & Zierler, 1990). The buddy/volunteer agrees to a

commitment of at least one year, but the implied term is a "lifetime" commitment in that the buddy/volunteer is expected to be a presence in the PWA's life until death comes.

A survey of buddy/volunteers revealed that they usually visit their buddy/PWA's home one or more times per week, often providing transportation with tasks such as shopping, cleaning, and meal preparation being done less often (Velentgas, Bynum, & Zierler, 1990). Over 60% of the buddy/volunteers spend six or more hours per week with their buddy/PWA (Velentgas, Bynum, & Zierler, 1990).

Thousands of buddy/volunteers across the United States have entered into this "profound commitment" (Velentgas, Bynum, and Zierler, 1990, p. 1378). The assignment to one client over a number of months, even years, makes for a unique, intense introduction into the life of another human being as she/he faces possible death.

Buddy Programs provide the "valuable, volunteer-based health care service that is critically needed by people with HIV (human immunodeficiency virus)-related illnesses" (Velentgas, Bynum, & Zierler, 1990, p. 1380). It is evident that buddy/volunteers make a difference

in the lives of persons with AIDS in a number of ways. A buddy/volunteer positively impacts the socialization of their buddy/PWA, helps in the management of that person's struggles with fear, provides hope, and is instrumental in total case management. Volunteers working with PWAs must be able to "deal with diverse situations and feelings" calling upon "exceptional strengths" (Dumont, 1988, p. 6). Buddy/volunteers are there to serve, enhancing care, giving hope to those who are in pain and on the brink of despair. The goal is "to make life a little better" for their buddy/PWA (Dumont, p. 7). The buddy/volunteer is an ally in her/his buddy/PWA's war against AIDS.

The Dynamics of the Buddy Relationship

The relationship begins as one member of the future buddy dyad calls the other. Telephone numbers are provided to both volunteers and PWAs by the affiliated AIDS service organization. An initial meeting is arranged.

The initial meeting is an extraordinary and unsettling blend of awkward moments, mundane chit chat, and discussions of life and death issues. The conversation is at best unusual as the dyad begins to plan for the future and set parameters. Each party

needs to evaluate if "it would work for [them] to be in a supportive relationship" with each other (Spurrier, 1993, p. 190). These are extraordinary goals for one initial meeting; however, AIDS casts a different slant on many constructs in one's life, including interpersonal relationships. The "newness" of the buddy/volunteer in the PWA's life is often a welcome change from the more established, longterm relationships maintained by the PWA from her/his pre-AIDS days. One buddy/volunteer put it this way: "He didn't really like being with people he'd had a history with and who had known him in a different way. I only knew him as someone with AIDS" (Spurrier, 1993, p. 191). The PWA is often comforted and relieved that interaction with the buddy/volunteer is without prior expectations regarding particular behaviors and/or her/his former appearance. It is acceptance and affection for who the PWA is at this point-in-time, rather than who she/he was in the past. This can eliminate a great deal of stress that the PWA might otherwise put on herself/himself to live up to the expectations of others. The buddy/volunteer comes with no previous interpersonal expectations and has been trained on the courses the disease can take so those

changes are met with differently than other caregivers or significant others (lovers, friends, family members) may be inclined to enact in the same situation.

A Call to Service

Reasons for volunteering for a buddy program are wide and varied, each person having their own unique motivations and stories to tell. Many volunteers serve as a way to "cope with the uncertainties and ambiguities of the CAIDSD epidemic," as a way to "bear witness" or because of a recognized need for whatever they might be able to give to the cause (Chambré, 1991, p. 535). The uncertainties of AIDS influence the motivations of the volunteers and the meanings they create from the process.

AIDS volunteering is not usually motivated by either altruism or self interest as are other health-related volunteer activities. The volunteers who serve as buddies are motivated in ways similar to those who join political/social movements. The providing of care to the PWA suggests involvement in a community and "a form of collective behavior, a way to respond to social change" (Chambré, 1991, p. 538).

The rewards of this type of service are immense. A buddy/volunteer typically reports personal growth,

learning much from the experience. One learns about life, struggle, and death in ways that would probably never otherwise be possible to discover. Buddy/volunteers are put to the test and are often surprised at their previously unbeknownst skills for adjusting, coping, improvising, communicating, giving, and self-disclosure. When individuals share the process of living with AIDS, and perhaps dying with AIDS, they are profoundly changed. One buddy/volunteer commented that "there's an almost indescribable joy at being able to connect with people, in this work, in the most profound and intimate way." He continued, "I walk in privileged places" when I walk with my PWA (O'Brien, 1992, p. 109). Another reflected that being a buddy/volunteer was "rewarding" because she witnessed "people taking control of their own lives" and parents coming to "the realization that their child is someone that they do love." This same buddy/volunteer summarizes what keeps her coming back day in and day out; it is that she "cares" for her buddy/PWA and she "wants to make sure Cher buddy] is being cared for." (O'Brien, 1992, p. 109).

Another buddy/volunteer explains his devotion to his volunteer role and his interactions with his

buddy/PWA: "You go right to the core, reaching out and connecting, often times on a very emotional level . . . I am very conscious of what a privilege that is" (O'Brien, 1992, p. 109). He further explains:

> Most of my life, I only concerned myself with my own well-being; my own pleasures, my own comforts. I never thought much about reaching out to other people, but there is an astounding, almost embarrassing sense of reward; when you can visit people and know that you have brought them comfort or brought them some ray of hope or brought them some bit of dignity (O'Brien, 1992, pp. 109-110).

Many buddy/volunteers reflect on how helping another individual prepare for the process of dying has profound benefits to their own process of living. One buddy/volunteer articulated:

> To be involved with someone's death and the whole process of dying, I can't imagine anything more intimate, it's just overwhelming, and the sense of privilege, is tremendous . . . [my buddy/PWA] makes me open my eyes . . . to him, to the worlds . . . other perspectives" (O'Brien, 1992, p. 110).

Living is learning. Volunteers involved in AIDS work have stories to tell about their experiences and what they have learned through their interaction with PWAs. The idea of a common community was echoed by one individual: "I'll tell you what I got out of this: the realization that everything is a chain and we are all interconnected" (Jarvis, 1992, p. 171).

Many buddy/volunteers reflect on their buddy/PWA's ability to see the beauty in life even as their health fails. PWAs are credited with teaching others "to appreciate the rainbows or to see God in others or to see a new side of ourselves" or how to find "joy and faith in the midst of pain" (Jarvis, 1992, p. 172). This education or inspiration often further bonds the buddy/volunteer to her/his assigned buddy/PWA. Perhaps the most important lessons to be learned are lessons about oneself. The benefits of such realizations can greatly outweigh any hardships necessitated by the volunteer experience. Reflecting on what can be gained by working with a PWA, one volunteer emoted: "I have learned to trust myself and believe in myself" (Jarvis, 1992, p. 174). A buddy/volunteer experiences much personal growth through the process of building a relationship with her/his buddy/PWA.

The Stigma of AIDS

Stigmas in U.S. culture are powerful determinants of attitudes and behaviors, affecting both the stigmatized and those doing the stigmatizing. In the United States, having AIDS is a stigmatized condition, borne out of previously created stigma surrounding homosexuality, addiction, poverty, and minority populations (issues often unwisely merged with the AIDS epidemic in U.S. culture). The stigma is further magnified as many members of U.S. culture possess irrational fears combined with a complete lack of adequate information regarding how AIDS is transmitted (Tallmer, 1990). Many members of the AIDS Culture are convinced that the general population constructs AIDS as "happening to . . . faceless 'risk groups'" and not "real people" (Callen, 1990, p. 8).

The stigma can lead to outright discrimination in areas of housing, employment, and medical care, as well as ostracization in various social settings. Because of negative interactional experiences within larger U.S. culture, many persons with AIDS and members of their support networks find solace, safety, freedom, and strength in their more welcoming co-culture, the Culture of AIDS.

The Culture of AIDS

One concept of culture suggests that humans are "suspended in webs of significance" they themselves have spun (Geertz, 1973, p. 5). Culture has also been described as the "software of the mind" (Hofstede, 1991). One less metaphorical definition suggests that culture is a "learned set of shared perceptions about beliefs, values, and norms, which affect the behaviors of a relatively large group of people" (Lustig & Koester, 1996, p. 35). Beamer and Varner posit:

> Culture is the coherent, learned, shared view a group of people has about life's concerns that rank what is important, instills attitudes about what things are appropriate, and prescribes behavior, given that some things have more significance than others (1995, p. 2).

This definition and its discussion of life centers around (one could include life with AIDS here) ranking what is important (focusing on living not dying, finding dignity in illness, etc.) and offers a useful framework through which to examine the Culture of AIDS.

Most buddy/volunteers become deeply enculturated into the AIDS Culture, which like other cultures, has

its own language, beliefs, meanings, norms, rituals, and sense of community. The culture helps define the disease and gives special meaning to the experience of being a buddy/volunteer and a buddy/PWA. The culture also uniquely defines the epidemic, the disease, the PWA, sexuality, death, religious traditions, the volunteer, and politics in the era of AIDS.

A central belief of this Culture is that a person who has been diagnosed with full-blown AIDS is not a "victim who is dying of AIDS" but rather a "person with AIDS" who is most definitely "living with AIDS" (Chambré, 1991). PWAs and their support systems (friends, lovers, family members, and volunteers) are empowered by the language that mirrors their emphasis on prolonging the life of the PWA. The Culture challenges others to "shift Ctheir] attitude Cabout PWAs] from Cpersons] 'dying with AIDS' to Cindividuals] 'living with AIDS.' And Cview them as people] living the best way Cthey] know how" (Grant, 1994, pp. 196-197). Being referred to as a "person with AIDS" as opposed to being labeled an "AIDS victim" is significant to one's construction of self. One man affirms this notion:

As a person with AIDS, I can attest to the

> sense of diminishment at seeing or hearing myself constantly referred to as an AIDS victim, an AIDS sufferer, an AIDS case--as anything but what I am, a person with AIDS. I am a person with a condition. I am not the condition (Navarre, 1988, p. 143).

Members of the AIDS Culture are supremely cognizant of how the construction of self affects the construction of life with AIDS. Though the term "construction" may not be overtly employed, members are innately mindful of the power of the process.

In the Culture a "person with AIDS" is entrusted with the goal and a set of activities that enable one to best live with AIDS, whereas an "AIDS victim" label implies that an individual must find a way to best die with AIDS. The word "victim" is summarily and consistently disenfranchised by the AIDS Culture.

Within this Culture, learning of one's HIV status and even the onset of AIDS is often understood as a "turning point," an "epiphany." The larger culture usually views the same series of events as a "death sentence" (Chambré, 1991). Another positive stance on the challenges of living with AIDS is represented by describing life with the potentially fatal disease as

being "awakened from a long afternoon nap to find the evening stretched before" one (Chambré, 1991, p. 536). The Culture finds beauty and meaning in the "evenings" of the lifetimes of persons with AIDS.

Other key elements of the AIDS Culture that the buddy/volunteer enters include a high value placed on dying with dignity, on helping others, on educating the public, and on reducing the stigma associated with the AIDS virus. An emphasis on quality over quantity of life is also strongly experienced within this Culture in which the buddy/volunteer serves.

Members of the AIDS Culture hold the belief that "love is a powerful tool and medicine" (Jarvis, 1993, p. 181). Love is not the stuff of greeting cards and romance novels--love is action. Love in the AIDS Culture is "caring, sharing, and serving;" it is not simply "words, theology, or philosophy" (Jarvis, 1993, p. 181). The Culture credits PWAs with challenging and teaching "the world to learn compassion, tolerance, understanding, and love" (Grant, 1994, p. 106). Coupled with love, hope is a powerful tool used in living with AIDS. PWA/activist/author, Michael Callen (1990), remarks that persons with AIDS:

need hope to survive. And when rational

> systems offer no hope, we turn to those systems that do. In our culture, that means religious systems that speak of life after death, of meaning to suffering, of a caring god (or goddess) who will take care of you (p. 186).

The AIDS Culture is also one that embraces diversity and acceptance. The political cause of AIDS and volunteering activities (formal and informal) at the heart of the Culture have brought together individuals whose paths may not otherwise have crossed. An open mind, rather than a unique set of past experiences or characteristics, is the requirement for membership. Cultural members understand that people can be different from one another but still understand love and kindness, and indeed grow to love each other as they serve together in the battle against AIDS/for people with AIDS. One member of the AIDS Culture suggests that "human beings are more alike than different, and recognizing the similarities can be far more constructive than emphasizing the differences" (Jarvis, 1992, p. 182). Embracing diversity is a norm of the Culture and the lives of members are tremendously enriched by it.

The AIDS Culture constructs our traditional meanings of death in exceptional ways and suggests that there is as much growth to be gained in the dying process as there is in the living process. Dying is constructed as a natural part of life, rather than merely the end of life. Life is more than just the time one spends on Earth. "AIDS reminds us that no one gets through life without dying. No one gets out alive" is the way one Culture member reflected on death (Jarvis, 1992, p. 148). Acceptance of the process is emphasized.

The AIDS Culture also includes a more active stance regarding death. PWAs are thought to be able to prolong their lives through a positive emotional state, aggressive health care, and the presence of a positive support network. As part of a PWA's support network the buddy/volunteer is an important member of the culture. Physical contact and emotional support offered by the buddy/volunteer are viewed as life-affirming parts of the process of living in the Culture of AIDS. Touching is an essential element to the work of a buddy/volunteer (Chambré, 1991) and the culture reinforces this in its rituals of demonstrative hugging, hand-holding, and other physical expressions of caring and concern.

The Culture places much faith in mainstream medicine, but does not scoff at alternative therapies. Culture members also reinforce the idea that one must be an active player in all healthcare matters. AIDS care is not just a medical issue but a political issue and a defining moment in the lives of cultural members. Buddy/volunteers may be galvanized by cultural norms promoting activism in the evolving AIDS policies by identifying areas for development, staffing political organizations which lack proper funding, and at the same instant creating ways to handle the sweeping social changes often simultaneously occurring in their own lives (Chambré, 1991). Persons with AIDS benefit greatly by the activist stance endorsed by the Culture. This benefit is not only in regard to the outcome, but also the process. One longterm survivor reflected that "politics is an antidote . . . and maybe even healing" (Callen, 1990, p. 187). The impact of the new Culture may be quite significant to the buddy/PWA, the buddy/volunteer, and ultimately the larger U.S. culture.

Upon becoming a member of the AIDS Culture your life is forever changed. Relationships pre-existing AIDS or the volunteer service are often altered because

of those individuals' lack of understanding about the Culture and its significance to life. One often develops a new set of criteria for evaluating people.

The AIDS Culture may be totally new to the buddy/volunteer, or the culture she/he has been a part of for some time, albeit in a different role. Each volunteer finds her/his own balance to "what was before" and "what is after" the AIDS epidemic impacted her/his life. One buddy/volunteer discloses, "the cruel irony of this kind of work: to do it, you join a community. Then you watch, helpless as that community disintegrates around you" (Nelson, 1990, p. 13).

Artifacts are one way culture outwardly manifests itself. Like other cultures, the AIDS Culture has its artifacts. Music is one such artifact. The Album Feeding the Flame: Songs by Men to End AIDS (1990) features multiple artists echoing themes reflecting values important in the AIDS Culture. Songs include "Gotta Lot of Livin' to Do," reinforcing the key construct of "living" rather than "dying" with AIDS, "Say a Prayer for a Stranger," calling both on community and renewed spirituality within the AIDS Culture, and the title cut, which celebrates AIDS activism, proclaiming "we are the ones who take to the

streets" (Sordillo, W., & De Caña, F., 1990, side 1). Another example is a song written by musicians Ron Romanovsky and Paul Phillips. The song is titled "Living with AIDS." The lyrics reinforce much about the meanings held prominent in the AIDS Culture:

> The loss of our lovers/Our sisters and brothers/Is a wound that cuts deep through our history of pride/And one way to heal/All the pain that we feel/Is to stand by the living and remain unified/So if you've got a friend/Whose condition is grim/Don't go burying them or drawing the shades/Surrender your doubt/To a person who's living with AIDS (Romanovsky & Phillips, 1994, side 1).

This stanza emphasizes the cultural values of reaffirming life, strong community, and activism in the battle against AIDS.

The song goes on to suggest "Living with love, not living in fear/Healing with hope, and drawing them near . . . Empowering people whose lives are at stake" (Romanovsky & Phillips, 1994, side 1) which reinforces the cultural value that being a PWA is about living rather than death, that members are indebted to help those suffering, and that service is about empowering

the PWA to draw on her/his own strengths.

Books and other textual artifacts also mirror the AIDS Culture. The stories told by its members are both informative and constitutive of the Culture. "People need to tell their stories. And . . . people need to hear others' stories" about lived experience surrounding AIDS (Jarvis, 1992, p. 183). The stories from this culture need to be shared to "validate, to affirm, to heal, to learn" (Jarvis, 1992, p. 183). Stories of experiences by those who are part of the AIDS Culture are told because they must be told. In the telling, the stories define goals, motivate, establish norms, reinforce values, construct meanings, and give "heartCsD a voice" (Jarvis, 1992, p. 184).

The AIDS Culture is continuing to impact the larger United States culture. The culture of this country can enhance its collective identity through modeling the tireless response to the AIDS epidemic seen in the AIDS Culture and by reaching out to persons with AIDS. Evidence of our shared, summative humanness is illustrated by the actions of some U.S. cultural members who have:

> set in place a skilled, humane network of concerned and trained human-service

> professionals and volunteers as our response to the AIDS epidemic. In so doing, we not only help persons with AIDS in a significant way until a definite medical break-through occurs, but we preserve our collective humanity and social solidarity against the impulse of indifference and cruelty (Lopez & Getzel, 1987, p. 53).

A closer examination of volunteers responding to AIDS is a worthwhile undertaking. Chapter 3 details the methodology of this research project which looks at one segment of the volunteer force in the U.S. who toil to alleviate the suffering of persons with AIDS.

Chapter 3

Methodology

Selection of Participants

Buddy dyad teams were sampled from a program sponsored by an AIDS-related organization in the District of Columbia, Virginia, and Maryland, with which I was once affliated as a volunteer. Metaphors were requested as responses to pencil/paper questionnaires from the approximately 300 dyads currently active in the buddy program at this research site.

Data Collection

Questionnaires were entrusted to the Buddy Program Coordinator who was to distribute them to team leaders at the regularly scheduled monthly meetings. Buddy dyads are placed on teams, and each team holds a monthly meeting for the buddy/volunteers, which is chaired by a buddy team leader. Team leaders meet once a month, by region, at the organization's headquarters or a branch office. The Buddy Program Coordinator was to visit those monthly meetings, explain the project, and request that Team leaders distribute questionnaire sets to each buddy/volunteer at the next regularly scheduled monthly meeting. A questionnaire set was

comprised of two questionnaires, one of which was boldly labeled "TO BE COMPLETED BY THE VOLUNTEER" and copied on white paper; the other questionnaire was unlabeled and on blue paper. Attached to each questionnaire was a pre-addressed, postage-paid envelope. Each buddy/volunteer was asked to complete the questionnaire labeled "TO BE COMPLETED BY THE VOLUNTEER." Buddy/volunteers were requested to deliver the unlabeled questionnaire with its attached envelope to their buddy/PWA. All participants were asked to mail completed forms within two weeks using the provided envelope.

Arranging the logistics required contacting the Buddy Program Coordinator from the AIDS service organization by fax, letter, and telephone. This proved inadequate in assuring that the methodology was followed exactly as designed. Significant alterations to the planned methodology included many surveys being mailed (by the Buddy Program Coordinator) to volunteer/PWAs rather than being presented to them by informed Team Leaders. This mass mailing of the survey, and a fabricated deadline, came about through unapproved actions made by the Buddy Coordinator entrusted with the surveys at the research setting.

These changes in the pre-planned methodology explain, at least partially, the lower than anticipated response rate. However, those surveys which were received proved invaluable in providing an understanding of the social construction of AIDS and the relationship dynamics of members of buddy dyads.

Confidentiality concerns of the participants were given utmost consideration as the study progressed. To help safeguard confidentiality, only the Buddy Program Coordinator and the Director of Volunteer Services were contacted (by telephone and faxed correspondence); no attempt to contact the buddies was ever made. At no time were participants' names requested or specific meeting times and locations revealed.

All questionnaires included the following text:

> I am requesting your participation in a study which will examine the experience of AIDS and the buddy program as revealed in the metaphors used by members of buddy dyads. A "metaphor" is the pairing of a word (or words) denoting one object, concept, idea, or feeling with another word (or words) to suggest a likeness or commonality between the two.

Please complete each of the phrases below, and return your completed questionnaire sometime within the next two weeks. A pre-addressed, postage-paid envelope has been provided. Note that all submissions will be confidential. Your name is not requested, but please answer the brief section near the end of the questionnaire that asks you to tell me a little about yourself.

Your participation in this research study is requested because of the unique insight you can provide others about life in the age of AIDS. Thank you in advance for your participation.

If you would like to review a copy of the completed research report you may request it from your Buddy Program Coordinator and it will be provided upon completion of the project.

Again, thank you.

Please complete the following phrases:

AIDS is

AIDS is

AIDS is

AIDS is

AIDS is

My buddy is

My buddy is

My buddy is

My buddy is

My buddy is

How many months have you been involved in the buddy program? _____

How many months have you been paired with your current buddy? _____

I am: MALE FEMALE (please circle one)

My buddy is: MALE FEMALE (please circle one)

Researcher's Point of View

My past experience as a buddy/volunteer, my values, and my political belief that there is a need for United States society to understand and reconstruct the many interrelated meanings surrounding the AIDS epidemic motivated me to conduct this study. Of further motivation is my recognition that there is a crucial need for AIDS to be kept on the "front-burner" of the political, healthcare, research, and social action agendas. Further, I believe that members of the public need to be presented with positive, constructive metaphors to help them recognize that the AIDS epidemic is a challenge to be undertaken, not a plague to be disavowed. My hope was that this research would produce such metaphors.

Analysis Procedures

As planned, the metaphors were analyzed to identify themes. This process began with the careful reading of all surveys; simultaneously, the five steps for identifying metaphors (Mooij, 1976), which were discussed in Chapter 2, were employed. All metaphors

were recorded in Tables 1 and 2 (see Appendix). Because many respondents chose to supply descriptors rather than the requested metaphors, such descriptors (all expressions that remained after metaphors were parcelled) were included in either Table 3 or Table 4 (see Appendix). The metaphors were then carefully reviewed until themes emerged, at which point recurring themes were each assigned a specific color. Thematizing proceeded as expressions on all tables were highlighted with appropriate colors. Additionally, categories of positive, negative, and judgmental were quantified for the purpose of determining the unique constructions of AIDS made by the buddies. An analysis of how these constructions differ from those of mainstream U.S. culture revealed discernible patterns. An understanding of these patterns, through an interpretation of how the subjects construct their experience of AIDS, uncovered values and beliefs pertaining to the AIDS epidemic and the Culture that has formed surrounding the epidemic. Also, the metaphors and descriptors provided an understanding of the participants' personal experiences as buddies. Themes and the supporting responses are presented in Chapter 4 which describes and analyzes the data obtained during this study.

Chapter 4

Results and Analysis

Results

Lengths of participation in the buddy program. The male buddy/volunteer respondents served as buddies for 15 to 120 months, an average of 51 months. They have been partnered with their current buddy/PWA an average of 14 months. The range of service reported by the male buddy/volunteers to their present buddy is 1 to 48 months. The female buddy/volunteers' tenure with the program ranged from 9 to 76 months, with an average of 27 months of service. They have been involved with their current buddy/volunteer for an average of 14 months. Involvement with their current buddy/PWA ranged from 2 to 40 months. The average length of service by buddy/volunteers of both sexes is 43 months.

The buddy/PWA respondents, all male, have been participating in the buddy program for an overall average of 36 months. These buddies have been in the program for 5 to 36 months, with a range of 1 to 24 months being assigned to their present buddy/volunteer. The average time with current buddy is 12 months.

The span of service for all participants range from 1 to 120 months with an average length of

participation of approximately 32 months, 13 months with current buddy.

Responses. The combined responses of all participants netted 57 metaphorical expressions about AIDS (see Table 1) and 32 concerning buddies (see Table 2). Supplementing the requested metaphors were 95 descriptive phrases or sentences about AIDS (see Table 3) and 121 about buddies (see Table 4).

All the metaphors and descriptors were supplied by the 33 returned surveys. The response rate was approximately 6% from the 582 questionnaires mailed (in sets of two) to the 291 buddy/volunteers. As previously stated, the low return rate is likely due to unapproved alterations to the planned methodology made by the Buddy Coordinator entrusted with the distribution of the surveys. Although these alterations are thought to have affected the return rate, it is believed that the quality of returned surveys was not diminished and that the number was sufficient to reveal, through analysis, significant patterns and themes.

Analysis

Themes and concepts revealed. The metaphors revealed themes and concepts associated with the lived experience of AIDS within the buddy dyads. The themes

that emerged were often ones thought to be integral to the Culture of AIDS which is believed to be embraced by the buddy dyad members. The following analysis answers research question one: "How do members of buddy dyads construct AIDS as revealed in their written metaphors?"

Metaphors and Descriptors about AIDS

Death. The buddies offered four metaphors of "AIDS is death," with one of those modified to "early death" and six more expressed a similar theme. The finality of the course of the disease was also metaphorically expressed as a "holocaust," "killer," and "destroyer of life." AIDS was also said to be the "plague," hearkening visions from epidemics of earlier times. "AIDS is loss" may also be a reference to loss of life, but this metaphorical meaning may be more inclusive to mean loss of health, stamina, security, friends, and so forth, as well as loss of life. "AIDS is a conditional existence" may also be construed as a veiled reference to death lurking in the shadows until the "conditions" are right to act. About 18% of the responses centered on the theme of death.

This is consistent with the social reality of those PWAs who have died before their time. The statistics and the experiences of the AIDS community

support this thought pattern, but it is significant that many of the death metaphors were followed by those implying more life-affirming or "AIDS as a challenge" cogitations. These more positive or proactive metaphors blended with the finality expressed by the death metaphors illustrate the disconcerting range of activities and emotions experienced daily by members of the AIDS Culture.

Descriptors reinforcing the theme of death include: "AIDS is a terrible disease that has taken many creative and talented people in their prime," "AIDS is taking my friends away from me," "AIDS is taking our best too soon," "AIDS is a disease which has taken the lives of far too many people," "AIDS is the reason I've lost people I loved," and "AIDS is losing your lover/partner and your closest friends--continuously." These all provide a glimpse of death that is routinely a part of the lived experience of members of buddy dyads. This was put concisely by two buddies: one wrote, "AIDS is fatal;" another replied, "AIDS is a very deadly disease."

Two buddies, both PWAs, focused on thoughts of death rather than the actuality of cessation of life. They commented that "AIDS is thinking much about one's

past and much about death, about the loss of career, and the absence of any purpose," and that "AIDS is dreading when a close friend falls seriously ill and hoping that somehow he will survive." This last descriptor, although its main focus is on death, also exemplifies that hope is still present.

Emotions reflecting the resiliency of the human spirit and emotions borne of adversity. Metaphors provide an understanding of how members of the AIDS Culture find inspiration as well as sorrow in the experience of living with AIDS. Nine metaphors reflected the more empowering emotions propagated in interaction between members of buddy dyads. These include: "AIDS is a form of truth," "an awakening," "a connection to the soul," and "an opportunity to experience joy for one good day."

One buddy echoes a primary sustaining philosophy present in the AIDS Culture, reporting that "AIDS is hope." Other metaphors echoing similarly uplifting sentiments include: "AIDS is a second chance for life," and simply "AIDS is compassion." These metaphors provide evidence that even in the sorrows of AIDS, one can find inspiration and testimony to the goodness to be found in self and others.

With the joy and inspiration lies sorrow as well. At least three of the metaphors reflect this dichotomy: "AIDS is a closing door; an opening door," "AIDS is a friend; an enemy," and "AIDS is an emotional roller coaster for the infected as well as the affected." Another buddy reinforced the AIDS Culture's emphasis on personal empowerment by reflecting "AIDS is what you make it." These metaphors further reveal the added complexity that AIDS brings to one's life and also demonstrate the adaptability of individuals in these stressful situations. The resiliency of members of the AIDS Culture is also depicted in that the positive aspects of life coexist with the negative ones and often triumph over them as well.

The metaphoric language reveals that the joys of community are significant, but tempered by intermittent anguish. Metaphors expressing sorrow include: "AIDS is sadness," "AIDS is a teardrop in my eye," and "AIDS is a silent cry in a sleepless night." An additional metaphor, "AIDS is fear," also relected a negative emotional construct. One buddy expressed his despair and also called for the non-verbal expressions of love and comfort so valued in the AIDS Culture; he wrote: "AIDS is the alienation and the need to be hugged, to

be held, to be accepted without fear." Descriptors expressing the angst of persons with AIDS include: "frustrating," "overwhelming," "tragic," "stifling," "nasty," and "scary." AIDS was also described by buddies as "isolating and lonely," "degrading to the individual," and "very mind stressing." The combination of metaphors and descriptors thematized here aptly call forth the sometimes woeful lived experience of the respondents as they contend with AIDS.

A wake up and call to action. Other metaphors and descriptors reflect more productive themes cultivated in the AIDS Culture. These include the positive outcomes of the disease such as a renewed sense of empowerment, and the previously unrealized inner-strength members find within themselves. These evolve from the creation of a community and its norms of service, education, and activism. AIDS metaphors created by members of buddy dyads reinforce that AIDS is not only a disease, but a political cause. Futhermore, all members of the Culture are held responsible for advancing that cause. Metaphors extolling the activism and community valued within the Culture include: "AIDS is a call to action for good-hearted people," "AIDS is a bond," "AIDS is an

opportunity to give and share," and "AIDS is an obligation to care and cry." Two respondents expressed, "AIDS is a teacher;" one added that AIDS "has taught many people about compassion and the frailty of life." These metaphors emphasize the commitment buddies have to: their cultural members, the moral cause of alleviating suffering, and the political cause of ending AIDS.

Some metaphors and their multi-levels of meaning illustrate a constructions of AIDS as a summons for humans to take the first steps in improving the lot of self and others. The metaphor,"AIDS is the smell of coffee; a wake up" implores members of the AIDS Culture and others to take on the challenges of stopping AIDS and helping people.

One aspect of the AIDS Culture is that it welcomes all types of people. AIDS brings together individuals who may have never even met if not for the disease touching their lives. As these relationships grow in significance, the circle grows, and a community is formed. Metaphors demonstrating this cultural value include, "AIDS is an opportunity to unite minority populations" and "AIDS is a part of our lives, all of ours."

This uniquely bonded community of buddies, comprised of individuals with varying ethnic, socioeconomic, and racial backgrounds and different sexual orientations, become remarkedly sensitive to the plight of others in U.S. Culture and expand their AIDS activism to encompass all political causes seeking to end bigotry. The AIDS Culture's awareness of outside ignorance is reflected metaphorically in: "AIDS is an excuse for bigots to hate," and "AIDS is a magnet for bigotry." Thus we see that social construction in the AIDS Culture has insights for our culture at large.

Two metaphors reflect on the acceptance of AIDS as an actuality by members of the buddy dyads and their Culture. "AIDS is perhaps a necessary evil" and "AIDS is reality" (noted by two respondents); each exemplifies a willingness to accept the task of battling AIDS and a recognition of AIDS as an existential fact.

The AIDS battle may be conceptualized as an all out war. Buddies who likened themselves to soliders in the cause created metaphors such as "AIDS is war," "AIDS is a battle to win," and "AIDS is the worst enemy I've ever imagined." "AIDS is evil" conjures up an image of the buddies as warriors in the struggle of

good against evil. This last metaphor also provides insights into the Culture's moral cause of ending human suffering and also countering the "evils" of homophobia, racism, classism, and all forms of hate borne of ignorance. Perceiving AIDS as a cause is both a call to activism and a statement of unity.

AIDS descriptors created by members of buddy dyads reinforce major themes of activism and community. Calling people to action, one respondent suggested that "AIDS is waking people up." Reinforcing the norm of solidarity within the Culture of AIDS are descriptors such as "AIDS is a part of our lives, all of ours," "AIDS is something we all live with but some choose to ignore," "AIDS is something we all need to know more about," and "AIDS is the reason I became 'involved.'" Other buddies formulated their feelings about AIDS, community, and the value of diversity in the following manner: "AIDS is a unique disease which has brought together many diverse groups to combat a common problem," "AIDS is the illness that has focused some of the best in people," and "AIDS is a disease which, while taking so much from us, has also taught us so much about sex, homosexuality, community, compassion, life, and death."

The Culture of AIDS holds the belief that while AIDS is a disease that one may have, it is not a punishment, a symbol of a particular lifestyle, nor any other such fallacious descriptors contrived by bigots or the culturally ignorant. Buddy-respondents reinforce this more enlightened perspective by confirming that "AIDS is random;" and "AIDS is not prejudice." Two respondents further conveyed the universality of AIDS in writing "AIDS is non-discriminating."

Concern for others is another norm significant to buddies and their Culture. This empathy is avowed by descriptors such as "AIDS is a condition which has hurt some of my buddies," and "AIDS is a disease which has touched me deeply."

Focus on the physical and the malady. Only six metaphors provided insight into the physical ravages of the disease. Since so much of the media of the larger culture focuses on chronicles of wasting, disease, and dying, the relatively small number of responses in this category may seem surprising; however, within the AIDS Culture it is the spiritual which is given prominence. Metaphors depicting the physical body include AIDS is: "suffering" (supplied by two respondents), "torture," and "pain" (offered by three of the responding

buddies). These metaphors may refer to the destruction of the body, although even these may denote the pain and suffering of the human heart or spirit over the physical. Although buddy/volunteers attend to the physical needs of their buddy/PWAs, their more important function is constucted as attention to less corporal needs; an ethic of care often flows both directions in the buddy dyad.

A number of AIDS descriptors created by members of buddy dyads provide basic information about the disease. Many include the word "disease" or "illness" and ranged from ones based on learned facts ("AIDS is Acquired Immune Deficiency Syndrome," "AIDS is an illness caused by a virus," "AIDS is a life-threatening illness," and "AIDS is an illness which destroys the immune system of a person") to ones that indicate the emotional impact of the lived experience of AIDS ("AIDS is a terrible disease," "AIDS is a cruel disease," "AIDS is a horrible disease," and "AIDS is a young man's disease"). Still other respondents discussed the less clinical aspects of AIDS. Their descriptors ("AIDS is a disease which has touched me deeply" and "AIDS is a disease which has overstayed its welcome!") depict what AIDS has meant to them emotionally; the latter

personification of AIDS as an unwelcome guest expresses the weariness of members of the AIDS Culture as their fight against AIDS continues into a second decade.

Many of the descriptors detail means of transmission and other medical information. These not only inform but highlight the AIDS Culture's value that members must also be teachers. Descriptors designed to teach are: "AIDS is a disease caused by the HIV virus," "AIDS is spread from one person to another by blood, semen, or dirty needles during drug use," and "AIDS is an attack of the immune system, leaving people vulnerable to infection without warning."

AIDS is also described as "painful," "crippling," and simply "a disease which I wish had never surfaced." This wish transcends all others in the Culture.

The greatest number (15) of descriptors in this category served to fuel the curable/incurable debate surrounding AIDS. Buddies holding a more hopeful outlook reflected: "AIDS is becoming less of a death sentence," "AIDS is beatable," "AIDS is treatable," and "AIDS is curable! We mustn't give up hope!" Continuing medical advances have given rise to increasing hope within the AIDS Culture. Two respondents acknowledge this hope, articulating: "AIDS is changing" and "AIDS

is a very difficult but tolerable disease."

Other buddies proclaimed AIDS to be:"incurable," "without a cure," "not treatable," and "nearly unstoppable." These may reflect the lived experience of many buddies to date, but does not preclude a more promising future. However, one buddy provided the bleakest of all responses, predicting that "AIDS is forever." This may run counter to the AIDS Culture's emphasis on hope, but may also reflect a more personal assumption about PWAs' life potential.

Another buddy chose not to engage in the debate, but rather offered a prayer, stating: "AIDS is something I hope they find a cure for soon."

Other metaphorical expressions about AIDS. A few metaphors resisted classification either because of their multiple interpretation potential or because of their all-encompassing nature. "AIDS is the desire to plant a seed, and see it flower and reach maturity" depicts despair, hope, life, and death within the context of living with AIDS. "AIDS is the sound of sand sifting through an hourglass" expresses the lived experience of being on the outside looking into life as that very life may be rapidly dwindling away. "AIDS is a ravaging forest fire" stands as testimony to how AIDS

so dramatically affects all the lives it touches.

The final AIDS metaphor, "AIDS is a mystery," provides insight into the ambiguity inherent in the AIDS Culture in which the buddy dyads interact.

Metaphors and Descriptors about Buddies

The research question: "How do buddies construct metaphors about their buddies, and what understanding can be gained about the experience of the buddy dyad relationship through an examination of these metaphors?" was answered through the process of thematization. Descriptors about buddies were also classified to enhance understanding of these unique caring relationships.

Friendship. The most commonly repeated metaphors supplied by the buddies reveal that the social construction of the buddy relationship is primarily realized as friendship rather than as a traditional client/caregiver relationship. "My buddy is a friend" was written by five respondents; four scribed "My buddy is my friend," and one added "My buddy is a good friend." Another buddy extended the theme, stating: "My buddy is a joy to have as a friend." Friendship was the most common metaphor expressed by both the buddy/volunteer and the buddy/PWAs.

The desciptors reinforce the construction of the buddy/volunteer's role as friend over that of caregiver. Descriptors about buddies created by buddy/volunteers included words and phrases that any individual might use to describe a close friend. The adjectives revealed that buddies are: "great," "upbeat," "curious," "pleasant," "giving," "caring," "gentle," "thoughtful," "accepting," "non-blaming," "kind," "funny," "wonderful!" and simply the "best!" Other descriptions delineated a buddy as "a decent person all around," "quite a conversationalist," and an "incredibly insightful" individual. Another respondent disclosed that his buddy "has an incredible outlook on life." Again emphasizing the value placed on friendship among members of the buddy dyad and in the Culture of AIDS, one response read: "My buddy is a person who is precious to his family and friends."

Buddy/PWAs' descriptors about their buddy also emphasized friendship. They described their buddy as: "witty," "intelligent," "compassionate," "kind," and simply "great!" Other PWAs elaborated that their buddy is: "someone I enjoy spending time with," and "one of the best people that have ever happened to me." PWAs also described their buddy as "the person closest to me these days," "who can still make me laugh," and "who 'drags' me out to

dinner, brunch, etc., when I don't feel like going (but I'm always glad when I go)."

The power of love is a tenet in the Culture of AIDS and buddies resounded this theme by disclosing: "My buddy is loved," "My buddy is able to love," and "My buddy is able to be loved." (Each of these statements was provided twice.) Another respondent provided the metaphor: "My buddy is love;" one added "My buddy is a lover." Two constructions revealed love to be a "gift;" one offered more detail, divulging that a buddy is a gift "that has given me a glimpse of unconditional love."

Friendship and love in the Culture of AIDS are often cultivated between members who, on the surface, seem unlikely candidates for a close relationship. However, the Culture's norm of embracing all types of people and its emphasis on community was called to mind as one respondent reflected that his "buddy is someone [he] would not have met but for the circumstances." This same respondent went on to praise their friendship.

Hero. Taking the the admiration borne of friendship to a higher level, a number of the reported metaphors attested to buddies' hero status. These came both from eight of the buddy/volunteers and a buddy/PWA with one of each stating directly that their buddy is a "hero." Three

respondents found their buddy to be the embodiment of "inspiration." One buddy/volunteer proclaimed: "My buddy is an incredible human being."

A specific kind of hero was also alluded to in the buddies' metaphors, that of the great military figure or the champion in battle. In these constructions, a buddy is a: "warrior," "soldier," "survivor," and "fighter." Another respondent posited that a "buddy is strength."

Descriptors provided about buddies also connote tales from heroic military conquests, including "angry," "strong," and "brave." All the allusions to heroes in life or in war bolster earlier metaphors that "AIDS is War." They also evoke the AIDS cultural value of personal responsibility and service to others, and symbolize the significance of the relationships formed in these dyads.

One PWA reported: "My buddy is a hero to me because he does so much not just for me, but for AIDS programs besides the buddy program, has a tremendously stressful job and life, and yet is always willing to listen to me." This metaphorical expression not only depicts the buddy as "hero" but goes on to trumpet activism in the community growing strong in the era of AIDS. One person with AIDS added "My buddy is working to end AIDS," a hero indeed in the Culture of AIDS.

Victim. The theme of victim was metaphorically offered by only one respondent, but is nevertheless worth noting. This singular victim metaphor ("My buddy is a victim") is noteworthy because the Culture of AIDS disputes the larger culture's view that every person who has contracted the disease is a victim. The emphasis on this concept is exemplified by the AIDS Culture's insistence on referring to one who has AIDS as a "person with AIDS," or a "person living with AIDS," rather than as an "AIDS victim," or "AIDS patient." Only one buddy supplied a metaphor violating this cultural norm; however, a number of descriptors have a more negative tone than the generally more positive metaphorical responses. These include comments that a buddy is: "so scared," "lonely (2)," "sad," "confused," and "depressed (2)," plus critical descriptors like "freakish," and "drunk." Descriptors implying victimhood suggest that a buddy is: "weak," "helpless," "so needy and pathetic."

Unfavorable metaphors include constructions that a buddy is: "sometimes a pain in the neck," and "a prodding pair of forceps." Such images of failings may be evocative of the great stress that the members of the dyads experience as they each construct life with

AIDS individually yet demonstrates the open, honest intimacy of the buddy dyad as well.

Other metaphorical expressions about buddies. Three metaphors about buddies defied categorization due to their sweeping sentiments or curiousness, but were noteworthy nonetheless. "My buddy is time well spent" calls forth images of making time in busy schedules, and of the rewards found in the buddy relationship. "My buddy is the other holiday" may imply that visits from buddies are a needed respite from the sameness of everyday life of either work or recuperation. Another unusual metaphor reported was: "My buddy is Prozac," which metaphorically compares a buddy to a drug that is commonly prescribed to relieve depression, suggesting that a buddy often brightens one's spirit through care, companionship, and conversation.

Conclusion

The yet undiscussed research question, posed prior to undertaking this research, is: "Do members of buddy dyads construct AIDS more positively, as, for example, a challenge (or series of challenges) to be met and overcome, more so than negatively, as in the metaphor 'AIDS is death,' or judgmentally, as in 'AIDS is the wrath of God?'" Analysis reveals that AIDS is more

often socially constructed by the research participants as a challenge than as certain death. Absolutely no metaphors or descriptors implied that AIDS is a punishment or any other such construction denoting guilt or judgment.

Metaphors revealed that AIDS is most often constructed as cohesion; as integral to community and activism in the Culture. Secondary constructions included death, emotional outpourings, and finally, malady.

Metaphors disclosed that a buddy is most often constructed as a friend. A secondary, but significant construction, is that buddies are heroes.

The metaphors and descriptors further suggest that buddy dyads are both life-affirming and significant relationships. The responses also reveal that members of buddy dyads living in the AIDS Culture construct AIDS in ways not often constructed by the rest of U.S. culture.

The remaining chapter proposes different stategies for investigating the lived experience of individuals impacted by AIDS.

Chapter 5

For Further Research

Several questions for additional research arise from this study. First, would a large sample, drawn from various buddy programs across the United States, expose different metaphor and descriptor themes specific to region of country or perhaps the particular AIDS service organization? One might examine the usefulness of metaphorical analysis as a predictor of success or failure of buddy/volunteer and buddy/PWA matches. Greater understanding of buddy dyad relational dynamics might provide buddy coordinators with useful insight into what support she or he could best offer to both members of the dyad. It would also be useful to ascertain if training programs could be tailored to reinforce productive constructions of the buddy experience and deter destructive ones sometimes enacted in the dyadic relationships. The identification of these trends would be the first important step of such research and conceivably metaphors could serve as important tools for such understandings. This seems valuable because it is reasonable to assume that members of the buddy dyads would operate from different perspectives than AIDS service professionals so it is

essential that buddy program coordinators and others involved in planning both initial and ongoing training programs be made aware of both the buddy/PWAs' and buddy/volunteers' lived experience.

Consideration to differences in constructions of AIDS and/or buddy relationship groups categorized by gender, race, ethnicity, age, religious, and socioeconomic concerns could be further explored to enhance our knowledge of how different member characteristics and circumstances impact the social construction of AIDS and related issues.

Learning more about the lived experiences of buddies through research surveys, such as the one conducted in this study, might be supplemented with metaphorical studies involving examination of either the requested or observed narratives provided by members of buddy dyads. It would be interesting to determine if such observations would reveal similar metaphors. The resulting data should enhance previous conceptions of these unique caring relationships sustained in the Culture of AIDS.

Longterm studies conducted within various organizations involving the same individuals over time might reveal how buddy relationships evolve.

Longitudinal studies conducted by sampling or observation, followed by metaphorical analysis and other types of inquiry, would be intriguing. The monitoring of the same individuals over time would increase our understanding of the social construction of reality of buddies as they respond to various changes in their Culture brought about by a fluctuating (perhaps more diverse) membership, advances in medical treatment possibilities for persons with AIDS, and whatever the future might have in store for the whole of U.S. Culture which also influences the co-culture of AIDS.

Metaphorical and narrative analysis with diverse subject groups could also further our understanding of the differing social constructions of realities concerning AIDS. Specific subject groups to be studied might include friends and family members of persons with AIDS, healthcare workers, AIDS service organization employees, members of the media, and the general population. The various subject groups could be studied to provide insight into ways to assist them in successfully performing their demanding roles in the era of AIDS.

One buddy contributed that "AIDS is part of our

lives, all of our lives." Accepting that this reality is upon us all mandates that any well-designed, non-deleterious research that provides a deeper understanding of the lived experience of all participants in the human drama of AIDS should be encouraged.

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Appendix

Table 1

AIDS Metaphors Created by Members of Buddy Dyads

Male Buddy/Volunteers

1. AIDS is a holocaust
2. AIDS is a killer
3. AIDS is an excuse for bigots to hate
4. AIDS is the modern plague
5. AIDS is a call to action for good-hearted people
6. AIDS is a magnet for bigotry
7. AIDS is perhaps a necessary evil
8. AIDS is fear
9. AIDS is a teacher
10. AIDS is a bond
11. AIDS is Hell
12. AIDS is a connection to the soul
13. AIDS is pain
14. AIDS is a conditional existence
15. AIDS is a holey canoe
16. AIDS is what you make it
17. AIDS is a punctured balloon
18. AIDS is a destroyer of lives
19. AIDS is an opportunity to give and share

(table continues)

Male Buddy/Volunteers (continued)

20. AIDS is an obligation to care and cry
21. AIDS is an opportunity to experience joy for one good day
22. AIDS is hope
23. AIDS is death
24. AIDS is a second chance for life
25. AIDS is the smell of coffee; a wake up
26. AIDS is war
27. AIDS is a ravaging forest fire
28. AIDS is a teardrop in my eye
29. AIDS is early death
30. AIDS is death
31. AIDS is reality
32. AIDS is an emotional roller coaster for the infected as well as the affected
33. AIDS is a part of our lives, all of ours
34. AIDS is a teacher that has taught many people about compassion and the frailty of life
35. AIDS is a silent cry in a sleepless night
36. AIDS is the sound of sand sifting through an hourglass

(table continues)

Male Buddy/Volunteers (continued)

37. AIDS is alienation and the need to be hugged, to be held, to be accepted without fear
38. AIDS is pain
39. AIDS is suffering
40. AIDS is compassion
41. AIDS is sadness
42. AIDS is loss

Female Buddy/Volunteers

43. AIDS is the desire to plant a seed and see it flower and reach maturity
44. AIDS is a closing door; an opening door
45. AIDS is torture
46. AIDS is a mystery
47. AIDS is an opportunity to unite minority populations

Male PWAs

48. AIDS is the worst enemy I've ever imagined
49. AIDS is evil
50. AIDS is death
51. AIDS is reality
52. AIDS is a form of truth
53. AIDS is pain

(table continues)

Male Buddy/Volunteers (continued)

54. AIDS is suffering

55. AIDS is a battle to win

56. AIDS is an awakening

57. AIDS is a friend; an enemy

No Female PWA Responses

Table 2

Metaphors about Buddies Created by Members of Buddy Dyads

Male Buddy/Volunteers

1. My buddy is a warrior
2. My buddy is a prodding pair of forceps
3. My buddy is sometimes a hero
4. My buddy is sometimes a pain in the neck
5. My buddy is love
6. My buddy is strength
7. My buddy is a victim
8. My buddy is a soldier
9. My buddy is a gift
10. My buddy is my friend
11. My buddy is a friend
12. My buddy is time well spent
13. My buddy is the other holiday
14. My buddy is Prozac
15. My buddy is hope
16. My buddy is a friend
17. My buddy is a survivor
18. My buddy is my friend
19. My buddy is my friend
20. My buddy is inspiration

(table continues)

Male Buddy/Volunteers (continued)

21. My buddy is a fighter
22. My buddy is a lover
23. My buddy is a gift to me that has given me a glimpse of unconditional love
24. My buddy is an inspiration
25. My buddy is a joy to have as a friend

Female Buddy/Volunteers

26. My buddy is a friend
27. My buddy is love
28. My buddy is my friend!
29. My buddy is a friend

Male PWAs

30. My buddy is a friend!
31. My buddy is a hero to me because he does so much not just for me, but for AIDS programs besides the buddy program, has tremendously stressful job and life, and yet is always willing to listen to me
32. My buddy is a good friend

No Female PWA Responses

Table 3

AIDS Descriptors Created by Members of Buddy Dyads

Male Buddy/Volunteers

1. AIDS is shrewd, crafty
2. AIDS is tragic
3. AIDS is a terrible disease that has taken many creative and talented people in their prime
4. AIDS is a disease that ironically brought people together and instilled a more universal sense of community
5. AIDS is becoming less of a death sentence
6. AIDS is Acquired Immune Deficiency Syndrome
7. AIDS is a disease caused by the HIV virus
8. AIDS is a terrible disease
9. AIDS is curable! We mustn't give up hope!
10. AIDS is a part of our lives, all of ours
11. AIDS is an illness caused by a virus (HIV)
12. AIDS is spread from one person to another by blood, semen, or dirty needles during drug use
13. AIDS is non-discriminating
14. AIDS is incurable
15. AIDS is something we all live with but some choose to ignore

(table continues)

Male Buddy/Volunteers (continued)

16. AIDS is a cruel disease
17. AIDS is something we all need to know more about
18. AIDS is taking my friends away from me
19. AIDS is the reason I became "involved"
20. AIDS is frustrating
21. AIDS is overwhelming
22. AIDS is human
23. AIDS is tragic
24. AIDS is beatable
25. AIDS is alive
26. AIDS is complete
27. AIDS is there, here
28. AIDS is forever
29. AIDS is devastating
30. AIDS is taking many friends
31. AIDS is changing
32. AIDS is not taken seriously by many
33. AIDS is sometimes silent, waiting, and hiding
34. AIDS is nearly unstoppable
35. AIDS is too devastating for words
36. AIDS is so painful
37. AIDS is a young man's disease

(table continues)

Male Buddy/Volunteers (continued)

38. AIDS is without a cure
39. AIDS is waking people up

Female Buddy/Volunteers

40. AIDS is devastating
41. AIDS is tragic
42. AIDS is ugly
43. AIDS is stifling
44. AIDS is crippling
45. AIDS is a horrible disease
46. AIDS is frustrating
47. AIDS is taking our best too soon
48. AIDS is random
49. AIDS is a terrible tragedy
50. AIDS is a unique disease which has brought together many diverse groups to combat a common problem
51. AIDS is a life-threatening illness
52. AIDS is an attack of the immune system, leaving people vulnerable to infection without warning
53. AIDS is an epidemic
54. AIDS is degrading to the individual
55. AIDS is horrible
56. AIDS is nasty

(table continues)

Male Buddy/Volunteers (continued)

57. AIDS is non-discriminating
58. AIDS is preventable
59. AIDS is a word that can scare the hell out of a person
60. AIDS is the illness that has focused some of the best in people
61. AIDS is an illness which destroys the immune system of a person
62. AIDS is a disease which I wish had never surfaced
63. AIDS is a condition which has hurt some of my buddies
64. AIDS is a disease which has taken the lives of far too many people
65. AIDS is unfair, ugly, hurtful, and devastating
66. AIDS is a disease which, while taking so much from us, has also taught us so much about sex, homosexuality, community, compassion, life, and death
67. AIDS is a disease which has overstayed its welcome!
68. AIDS is is a disease which has touched me deeply
69. AIDS is deadly
70. AIDS is not prejudice

(table continues)

Male Buddy/Volunteers (continued)

71. AIDS is incurable
72. AIDS is not treatable
73. AIDS is scary

Male PWAs

74. AIDS is losing your lover/partner and your closest friends--continuously
75. AIDS is never feeling well again
76. AIDS is thinking much about one's past and much about death, about the loss of my career, and the absence of any purpose
77. AIDS is not really knowing any happiness but knowing what grief and constant depression are all about
78. AIDS is dreading when a close friend falls seriously ill and hoping that somehow he will survive
79. AIDS is fatal
80. AIDS is treatable
81. AIDS is inconvenient
82. AIDS is responsible for my family's rejection of me as a person
83. AIDS is misunderstood by my family
84. AIDS is the reason I've lost people I loved
85. AIDS is isolating and lonely

(table continues)

Male PWAs (continued)

86. AIDS is a very difficult but tolerable disease

87. AIDS is very mind stressing

88. AIDS is fucked up

89. AIDS is without a cure

90. AIDS is waking people up

91. AIDS is something I contracted years ago

92. AIDS is a very deadly disease

93. AIDS is a part of my life

94. AIDS is ?* the immune system

95. AIDS is something I hope they find a cure for soon

No Female PWA Responses

* a "?" denotes that the word could not be deciphered because of handwriting style

Table 4

Descriptors about Buddies Created by Members of Buddy Dyads

Male Buddy/Volunteers

1. My buddy is alive
2. My buddy is capable
3. My buddy is able to love; able to be loved
4. My buddy is a human being
5. My buddy is freakish
6. My buddy is clotted ?* with little flowing forth
7. My buddy is constant, almost unbearably so
8. My buddy is so scared
9. My buddy is so brave
10. My buddy is so needy and pathetic
11. My buddy is the best
12. My buddy is so thankful to feel well now
13. My buddy is lonely for family
14. My buddy is someone to care and cry for
15. My buddy is full of compassion
16. My buddy is hard to reach
17. My buddy is happy one minute and depressed the next
18. My buddy is a giving person
19. My buddy is upbeat
20. My buddy is working to end AIDS

(table continues)

Male Buddy/Volunteers (continued)

21. My buddy is a proud father
22. My buddy is dying
23. My buddy is drunk
24. My buddy is sad
25. My buddy is alive
26. My buddy is dying inside
27. My buddy is strong
28. My buddy is realistic
29. My buddy is curious
30. My buddy is confused
31. My buddy is depressed
32. My buddy is a great source of inspiration for me
33. My buddy is suffering and I can't do anything to help
34. My buddy is lonely
35. My buddy is an incredible human being
36. My buddy is a real pleasant guy
37. My buddy is someone I would not have met but for the circumstances of the buddy/client relationship
38. My buddy is a ?*, giving, and caring person
39. My buddy is quite a conversationalist
40. My buddy is great; he makes me feel good

(table continues)

Male Buddy/Volunteers (continued)

41. My buddy is going at it one day at a time
42. My buddy is making his days add up!
43. My buddy is a very gentle and thoughtful guy
44. My buddy is really "growing up" as a result of facing the various issues related to his disease
45. My buddy is someone who has taught me a lot about being grateful and less judgmental
46. My buddy is strong
47. My buddy is accepting
48. My buddy is non-blaming
49. My buddy is lucky
50. My buddy is loved
51. My buddy is strong
52. My buddy is brave
53. My buddy is gone (this respondent noted that his buddy/PWA had died less than three weeks ago)

Female Buddy/Volunteers

54. My buddy is a gentle, kind man
55. My buddy is a thoughtful person who supports my struggle and provides me with companionship
56. My buddy is funny
57. My buddy is a decent person all around

(table continues)

Female Buddy/Volunteers (continued)

58. My buddy is a big Black man with whiskers
59. My buddy is scared
60. My buddy is young
61. My buddy is kind
62. My buddy is loved
63. My buddy is dead
64. My buddy is dying
65. My buddy is aggressive
66. My buddy is not a nice person
67. My buddy is a drug abuser
68. My buddy is scared
69. My buddy is secretive
67. My buddy is always sick
70. My buddy is wonderful
71. My buddy is living with AIDS
72. My buddy is doing well
73. My buddy is reluctant to ask for assistance
74. My buddy is a person I want to help
75. My buddy is usually a man
76. My buddy is someone who needs my help
77. My buddy is a person who is precious to his family and friends

(table continues)

Female Buddy/Volunteers (continued)

78. My buddy is someone who might have had a long life
79. My buddy is incredibly insightful
80. My buddy is wonderful!
81. My buddy is lonely and would love a one-on-one relationship
82. My buddy has an incredible outlook on life
83. My buddy is frightened
84. My buddy is not eager to include people in his thoughts
85. My buddy is angry
86. My buddy is often in pain he cannot share
87. My buddy is bisexual
88. My buddy is Afro-American
89. My buddy is male
90. My buddy is a father of three
91. My buddy is dying

Male PWAs

92. My buddy is alive
93. My buddy is capable
94. My buddy is able to love
95. My buddy is able to be loved
96. My buddy is a human being

(table continues)

Male PWAs (continued)

97. My buddy is great!
98. My buddy is helpful!
99. My buddy is cooperative, beautiful, accommodating and she helps me a great deal with my transportation
100. My buddy is witty
101. My buddy is intelligent
102. My buddy is compassionate
103. My buddy is very supportive emotionally
104. My buddy is concerned about my well-being
105. My buddy is kind
106. My buddy is amazing
107. My buddy is extraordinary
108. My buddy is non-compliant
109. My buddy is depressed
110. My buddy is strong
111. My buddy is weak
112. My buddy is brave
113. My buddy is helpless
114. My buddy is one of the best people that have ever happened to me
115. My buddy is the person closest to me these days
116. My buddy is the person who can still make me laugh

(table continues)

Male PWAs (continued)

117. My buddy is the person who "drags" me out to dinner, brunch, etc., even when I don't feel like going (but I'm always glad when I go)
118. My buddy is someone who can squeeze 48 hours of work, etc., into any 24 hour day
119. My buddy is someone I call upon in times of need
120. My buddy is very caring towards this issue
121. My buddy is someone I enjoy spending time with

No Female PWA Responses

Notes: 1) Two respondents completed "My buddy is" with a name; these responses were omitted.

2) one respondent changed the "is" to "was" on her survey responses and noted that she had "lost" her buddy two weeks ago; printed "is" was maintained for the sake of consistency.

* a "?" denotes that the word could not be deciphered because of handwriting style